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ABSTRACT

This survey sought to identify the status of state policies on Individual Family Service Plans (IFSP) required by Public Law 99-457. The survey found that every state plans to develop or review IFSP policies, even the three states who said they had existing policies which they thought might currently meet the Part H requirements on service delivery to infants/toddlers with disabilities and their families. The Interagency Coordinating Council was identified as a key participant in policy development in 37 of the 39 states which had identified procedures for input into or review of the IFSP policies. The lead agency was the most frequent agent for final policy approval. Content analysis of seven states' policies found that the policies included a case management system, family input into plan development, and requirements for identifying family needs. However, few policies identified practices to protect the rights of the family, and none identified procedures for resolution of disputes. An appendix contains the questions used in the content analysis of existing state policies. (Author/JDD)

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STATE PROGRESS IN POLICY DEVELOPMENT FOR THE INDIVIDUALIZED FAMILY SERVICE PLAN (P.L. 99-457, PART H)

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Principal Investigator
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Program

EXECUTIVE SUMMARY

A telephone survey of all states and the District of Columbia was conducted by the Carolina Policy Studies Program (CPSP) in the summer of 1988. One of the goals for this survey was to identify a baseline about the status of existing state policies having to do with the Individual Family Service Plan (IFSP) policies. A second purpose was to begin to catalog states' plans for activities to develop policies if such did not yet exist. Of particular interest in this first round of surveys was identification of the key participants in the decision-making process.

The National Association of State Directors of Special Education (NASDSE), under sub-contract to the CPSP, conducted the analysis of the sections of the survey having to do with these family issues. NASDSE also developed a draft framework for the content analysis of the components of existing state policies focusing on the IFSP and family involvement.

Every state plans to engage in activities to develop or review IFSP policies. Even the three states who said they had existing policies which they thought might currently meet the requirements of Part H of PL 99-457 indicated that they intended to review these existing policies to insure that they do conform and to determine if any changes need to be made in them.

It appears that the Interagency Coordinating Council (ICC) is being involved extensively in the development of these policies. The ICC was identified as a key participant in 37 of the 39 states who had identified procedures for input into or review of the IFSP policies. The lead agency appears to be the most frequent agent for final approval of these policies but the ICC, the legislature or governor, or some other entity were also cited as final authorities.

Seven states submitted policies for content analysis, four of which were drafts of policies. These policies included many family elements, including a case management system, family input into the plan development, and requirements for identifying family needs. However, few of the policies submitted for analysis currently identified practices to protect the rights of the family, and none of the policies relating directly to the IFSP identified procedures for resolution of disputes.

The legislative attempts to provide families with a greater voice in the programs for their own children have increased substantially over the past few years. This increase appears to be the result of a strong parent advocacy movement (Turnbull & Turnbull, 1986; Edelman, 1987) and a substantial body of research that confirmed the important role that the family plays in the adaptation of their children with handicapping conditions (Gallagher & Vietze, 1986).

One of the consequences of such legislative emphases is that professionals have had to change some of their traditional ways of interacting with families and to modify their procedures for working with families. The 1986 Amendments to the Education of the Handicapped Act (P.L. 99-457, Part H) has emphasized the requirements of family participation in the programming for infants and toddlers with handicapping conditions. This report will document the initial steps that the fifty states have taken to meet these requirements in the process of implementing this legislation.

Part H of the Education of the Handicapped Act (EHA), as enacted by PL 99-457, describes a process for providing services to infants and toddlers with special needs and their families. One of the unique components of this process is the substantial emphasis on the involvement of the family in the design and provision of early intervention services. The policies which a state develops with respect to family empowerment and involvement will reflect the conceptual and attitudinal foundations of the entire program. It is essential for any comprehensive policy analysis of Part H to identify

the strategies states employ and the parameters they define with respect to the family's role in early intervention.

Major provisions of Part H, the Handicapped Infant or Toddler Program, require and describe the Individualized Family Service Plan (IFSP). The law specifies that each infant or toddler with handicaps and his or her family shall receive a written Individualized Family Service Plan developed by a multidisciplinary team, including the parent or guardian.

The law states that the IFSP shall contain;

- a statement of the infant's or toddler's present level of development,
- a statement of the family's strengths and needs relating to enhancing the development of the family's infant or toddler,
- a statement of the major outcomes expected to be achieved for the infant and toddler and family,
- a statement of the specific early intervention services necessary to meet the unique needs of the infant, toddler, and the family,
- the projected dates for initiation of services and the anticipated duration of such services,
- the name of the case manager, and
- the steps to be taken supporting transition to services provided under Part B of EHA, if necessary.

Additional provisions specify evaluation components and call for periodic review.

Supplementary information provided in the Notice of Proposed Rulemaking (NPRM)[1] restates that the family is to play an active

[1] Notice of Proposed Rulemaking - Federal Register November 18, 1987

role in the planning and provision of early intervention services. The NPRM states that IFSPs are based, in part, on the IEP requirements (referring to the Individual Education Plan (IEP) mandated in P.L. 94-142) but that there are some distinct differences: "For example, the required content of the IFSP is more comprehensive than the IEP, and includes several components that go beyond the scope of the IEP" (NPRM, Federal Register, 11/18/87).

The law and NPRM are silent about many issues which will determine the nature and format of the IFSP. It may be that the regulations guiding the implementation of this mandate may address some of these issues but it appears that a major emphasis of this program is to allow states many options and great flexibility in program development. States have discretion over many aspects of the IFSP and considerable variability among states can be expected.

METHODOLOGY

In the summer of 1988, the Carolina Policy Studies Program (CPSP) conducted a telephone survey of the 50 states and the District of Columbia (see Harbin, Terry & Daguio, 1988). One section of this survey dealt with states' plans and actions-to-date to develop IFSP policies. The survey was designed as a structured interview, similar to a clinical interview, with prepared "probe" items. It was anticipated that states would be at varying stages in their development of these policies so this interview technique was selected because it offered optimum flexibility while ensuring commonality of responses on some issues. This more open-ended

interview approach has proven to be an extremely useful first step in conducting policy research.

All 50 states and the District of Columbia (referred to as a state in this document) responded to the survey. The responses from the survey were coded by two judges acting independently and by, Patricia Place, the senior investigator. Reliability among the coders was greater than 80% although, given the limited time scope of the study, there had been no opportunity for prior joint training in coding. Judgments to resolve differences were made by the senior investigator.

States who indicated that they did have a policy about the IFSP were asked to send these statements for further analysis. Major issues regarding the IFSP and other family policies were summarized, and an initial version of the coding form was developed to analyze policies. The items in this content analysis were based upon the components of Part H of PL 99-457 and the major issues under discussion in the field about IFSP policies. Members of the CPSP Advisory Committee, the CPSP Family Advisory Board, and other professionals provided input about the 'best practice' items which should be contained in the review.

Appendix A to this report presents the questions that formed the basis of the content analysis of existing state policies. The four areas of analysis included the policies regarding the IFSP process; the identification of family needs and resources, the content of the IFSP, and family rights and protections.

FINDINGS

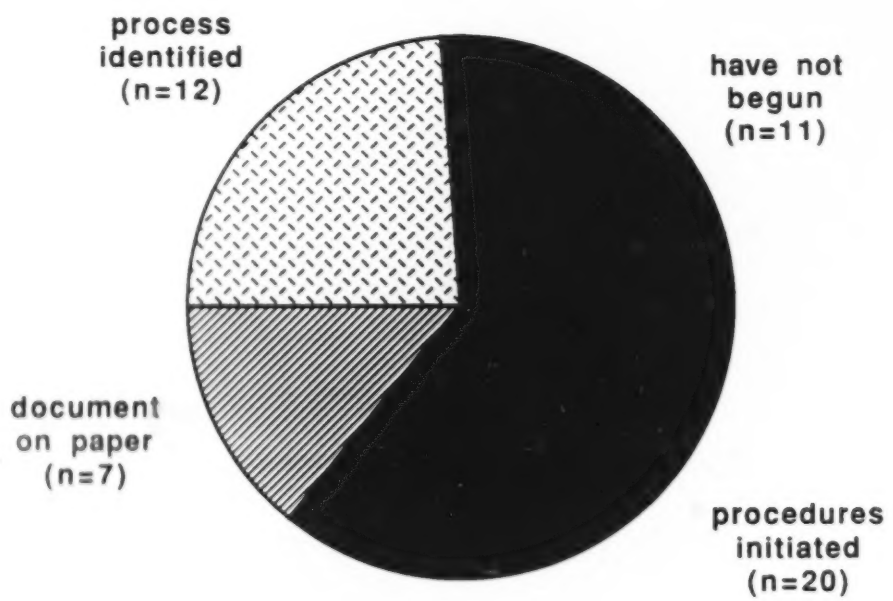
STATUS OF IFSP POLICY DEVELOPMENT

Prior to the passage of PL 99-457, all states were providing early intervention services to some infants and toddlers with special needs and their families (Walsh, Campbell, & McKenna, 1988). The current survey found that these services were guided by a number of different program plans. Programs used Individualized Developmental Plans (IDPs), Individualized Program Plans (IPPs), Individualized Habilitation Plans (IHPs), Individualized Education Plans (IEPs), and other plans. Some states had state level regulations guiding the development of these service plans, some had guidelines, while some states allowed local service providers autonomy in developing plans. Most of these plans were primarily child -focused not child and family centered as will be required in the IFSP.

According to the states' responses to this survey, eight states (see Figure 1) currently had state policies for Individualized Family Service Plans. Seven of these states forwarded its policies for an in-depth analysis; one state was not ready to disseminate their policies because these were in very early draft form. Policies pre-dating PL 99-457 included regulations from two states and guidelines from a Policy and Procedures manual from another. Policies developed after PL 99-457 included one state's draft regulations, one state's draft guidelines, and two states' IFSP forms, with directions, which were being piloted in each state. These will be discussed in detail later in this paper.

FIGURE 1

Status of states' development of IFSP policies



Of the remaining 43 states who responded that they did not have policies about the Individualized Family Service Plan, 12 states stated that they had identified the processes which would be employed to develop policies about IFSPs but had not yet initiated activities, and 20 states reported that they had started the process of developing IFSPs. The remainder (n = 11) said they had not yet made decisions about addressing this component. In some cases, states mentioned that they were pursuing other activities, e.g., some had been vigorously pursuing areas of policy development primarily having to do with the issues of eligibility and definitions. Some states mentioned having had changes in their Interagency Coordinating Council (ICC) or ICC staff as delaying their anticipated accomplishments to date.

Although not specifically addressed in the current survey, many states commented on the processes they will use to develop these policies. It appears that states are utilizing multiple processes in attempting to develop policies about the IFSP. The most frequently cited process was to fund pilot studies (n=16). Several states each cited one or more of the following: using a consultant, developing a position paper, and/or funding studies.

WHO ARE THE PARTICIPANTS IN DEVELOPING IFSP POLICY?

In the telephone survey, states were asked to identify the key participants in their policy development process. These questions addressed who wrote or will write the policy, who provided or will provide input and review, and who would give final approval to the

policy. As Harbin, et al., (1988) noted in their analysis of the section of this survey dealing with definitions and eligibility issues:

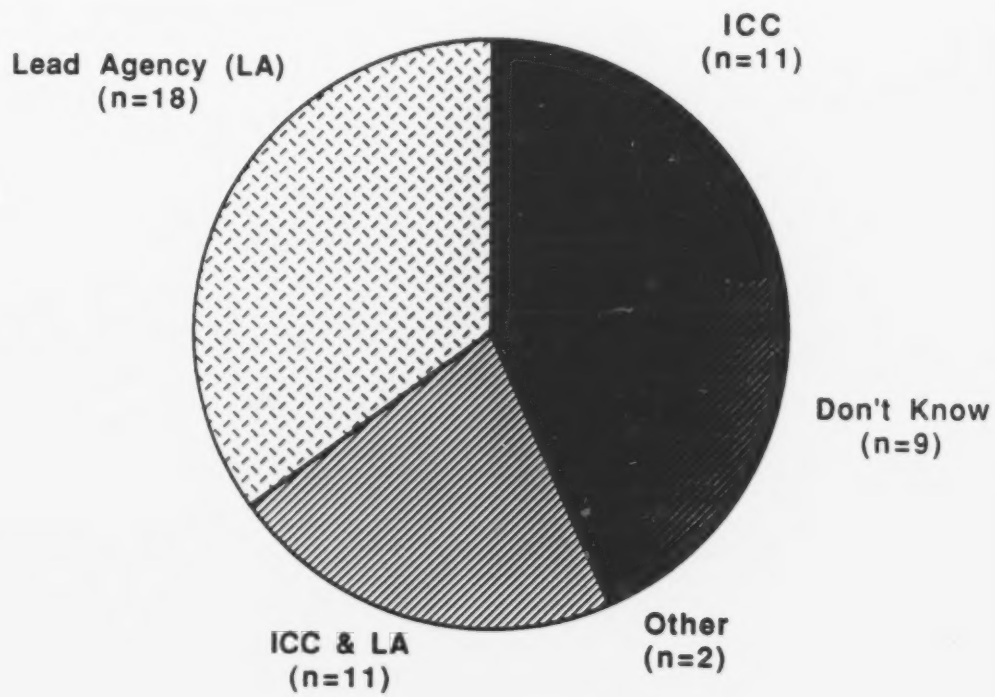
> For most states the policy development process is not completed. Therefore, respondents were able to answer for some questions what has actually occurred, while for later steps in the process they were required to speculate (pg. 4).

Who will write the family policies? Figure 2 summarizes the data generated when states were asked who will write the IFSP. If the ICC or a subcommittee of the ICC was identified these responses were coded as ICC. When the "lead agency", a task force led by it, or a subcommittee including lead agency representatives but not identified as being under the direct auspices of the ICC, were mentioned these were coded as lead agency. When the respondent clearly indicated that both the lead agency and the ICC jointly were involved in the activity this was coded as both. (See Figure 2)

- A majority of states said that the lead agency would write the policies (n = 18). Of these, one state said that the lead agency would write the policy with the help of a consultant and one said the lead agency and service providers and others would write it.
- The Interagency Coordinating Council, or a subcommittee with at least one member from the ICC, will be responsible for writing the IFSP policy in 11 states. Of these, one state said the ICC, or a subcommittee of the ICC, would write it in conjunction with a consultant.
- Both the lead agency and the ICC jointly will write the policy in 11 states.
- Two states said others would write the draft IFSP. In one the draft would be written by the pilot projects and in the second the draft would come through an interagency task force.
- The remaining 9 states were not sure who would take the lead in actually writing the IFSP.

FIGURE 2

States who have identified which agency has the primary responsibility for writing the IFSP policy



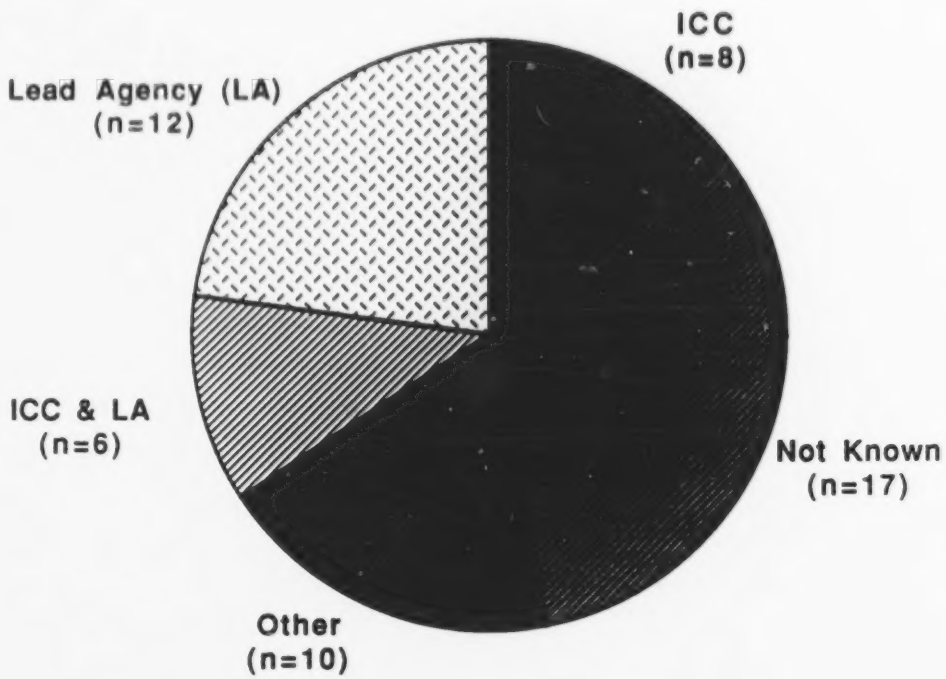
Who will provide input into and/or review the family policies? The interagency collaborative nature of the development of these policies was very evident by the number of states who cited many contributors to both the input and review of the proposed policies. Of the 39 states who had identified those to provide input and/or review, 37 included input or review from the ICC, or a subcommittee of the ICC. The two states which did not specifically designate the state ICC as having input or review involvement both said that they historically had policies emphasizing and preserving local autonomy. Both these states said that they would receive input and review from local ICCs. However, given the open ended nature of the interview protocol, one cannot necessarily conclude that the state ICC will not be participating in this process also.

States volunteered that many others, including among them, parents and advocates, service providers, and consultants will also be, or have been, consulted for input. Additional input or review is being sought in some states by holding public hearings or field testing. Some states (n=12) had not yet finalized who would be involved in providing input.

Who will approve the family policies? Finally, states were asked who had the authority for final approval of the IFSP policies (see Figure 3).

FIGURE 3

Number of states indicating mechanism for final approval for IFSP policies



- The lead agency, or the commissioner or administrator of the lead agency, was most often cited as being presumed to have final authority about the state's policies (n = 12).
- Lead agencies with the ICC or the ICC solely were cited by 6 states each.
- A variety of other sources that were needed for state approval were identified: the legislature or governor (n = 3); the lead agency and the governor (n = 1); the ICC and the legislature (n = 2); the lead agency, the ICC, and the governor (n = 1); a state board (n = 1); a state board and the lead agency (n = 1); and an executive agencies council (n = 1).
- At this early date, 17 states did not know who would approve the policies.

What components were included in state family policies?

Policies from seven states were examined. This is not a sufficient source from which to draw conclusions but identification of the components of these can be illustrative to those interested in the status of states' policies relating to the IFSP and other family issues at this time. What represents a "policy" may vary from state to state, and such was the case in this instance. Two of these policies consisted of regulations which pre-date PL 99-457, one is dated 1983 and the other 1984; one set of guidelines was dated 1981. These three states, while volunteering their current policies, also related that the current policies are under review. As will be seen, these policies are in many ways forerunners of the Part H requirements as they include many references to family involvement.

Policies in two states submitting information to this study consisted of model formats and guidelines drafted after PL 99-457. Another state has post PL 99-457 draft regulations and, one has

written information and guidelines for the IFSP planning process. The following is a brief summary of the existing policies.

Table 1 provides a summary of the content analysis of the states IFSP policies. Regarding the processes involved in developing the IFSP, all seven state policies require a written plan, indicate a case management system, and identified an IFSP planning process which included family input into that process.

None of the policies reviewed specified how the case manager was to be selected or how the case manager could or would be changed. Three of the PL 99-457 drafts included specific timelines for some services. All but two of the state policies mentioned multi-disciplinary evaluation in some fashion; while a different set of five indicated parental input into the evaluation. Provision of services according to principles of normalization and in the least restrictive environment were addressed in three state policies.

The identification of family needs and strengths is a current topic being discussed widely among policy makers and those interested in the implementation of these policies. All seven state policies addressed a system for identifying family needs while five of the seven included identifying family strengths. Only three of the state policies addressed, even minimally, how these needs and strengths were to be identified or who would be the identifier. Only one of the policies defined a "parent" and none defined a "family". Concern about the need to consider unique cultural needs or strengths of families were contained in three policies.

TABLE 1

CONTENT ANALYSIS OF STATE IFSP POLICIES[1]

Features of IFSP Policies	STATES A	B	C	D	E	F	G	Total
Policies Regarding Processes:								
Must each IFSP be written?	X	X	X	X	X	X	X	7
System of case management mentioned?	X	X	X	X	X	X	X	7
Specification of how case manager selected?	-	-	-	-	-	-	-	0
Provisions for changing case manager?	-	-	-	-	-	-	-	0
Policies Regarding Multidisciplinary Assessment:	X	X	-	X	X	X	-	5
Is family assessment input indicated?	-	X	X	X	X	X	-	5
Policies Regarding IFSP Process:								
Is a planning process indicated?	X	X	X	X	X	X	X	7
Is family indicated in the process?	X	X	X	X	X	X	X	7
Is normalization indicated	-	X	X	-	-	X	-	3
Do policies address unique cultural strengths/needs?	-	X	X	-	X	-	-	3
Policies Regarding Timelines:								
Is there a timeline for completion of the evaluation?	-	-	-	X	X	-	-	2
Is there a timeline for development of IFSP?	X	-	-	X	X	-	-	3
Is there a timeline for initiating services?	-	-	-	-	X	-	-	1

[1] Items on this table correspond to respective items in Appendix A. A total of 7 states' policies were analyzed. Three provided guidelines or regulations developed prior to P.L. 99-457; four provided guidelines, regulations, or formats developed after P.L. 99-457 and two of these were in draft form.

TABLE 1 (CON'T)

Features of IFSP Policies	STATES A	B	C	D	E	F	G	Total
Policies Regarding Identification of Family Resources and Needs:								
Is "family" defined?	-	X	-	-	-	-	-	1
Is there a system for identifying family strengths?	-	X	-	X	X	X	X	5
Specification of how family strengths are identified?	-	-	-	-	X	X	X	3
Is there a system for identifying family needs?	X	X	X	X	X	X	X	7
Specification of how family needs identified?	-	-	-	-	X	X	X	3
Specification of who will identify family strengths & needs?	-	-	X	-	-	X	X	3
Policies Regarding What the IFSP Form Will Contain:								
Statement of child's current level of development?	-	X	X	X	X	X	X	6
Statement of how family strengths and needs relate to enhancing child's development?	-	X	X	X	X	X	X	6
Statement of major outcomes?	X	X	X	X	X	X	X	7
Statement of services needed?	X	X	X	X	X	X	X	7
Statement regarding frequency of services?	-	-	-	X	X	X	X	4
Statement regarding intensity of services?	-	-	-	-	X	X	X	3
Specification of method of delivering services?	X	X	-	X	X	X	X	6
Specification of projected dates of initiation of services?	X	X	-	X	X	X	X	6
Statement regarding duration of services?	X	X	X	-	X	X	X	6
Case manager specified?	-	-	-	X	X	X	X	4
Steps taken to support transition?	-	X	-	X	-	X	X	4
Time periods for review specified?	X	-	X	X	X	X	X	6

TABLE 1 (CON'T)

Features of IFSP Policies	STATES							
	A	B	C	D	E	F	G	Total
Policies Regarding Family Rights and Protections:								
Provisions for protecting privacy?	-	X	-	-	X	-	-	2
Consent required and defined?	-	X	-	-	X	X	-	3
Confidentiality of records specified?	-	X	-	-	X	-	-	2
Coordination among agencies addressed?	X	X	X	X	X	-	X	6
Determination of payment of services?	-	X	X	-		X	X	4
Procedures for resolving disputes regarding financial responsibility?	-	-	-	-	-	-	-	0
Procedures for individual conflict resolution?	-	-	-	-	-	-	-	0
Procedures for resolving systemic conflicts?	-	-	-	-	-	-	-	0
Choices regarding level of family involvement?	-	X	-	-	X	-	-	2

The form of the IFSP is important in that it translates policy and legislation into procedures and actions. All but one of the state policies contained a provision for including information about the child's present level of development and a statement of the family's strengths and needs. All of them included the intended outcomes or goals of intervention and a listing of the services to be provided. Six states made some mention of the need to include the method of the delivery of services, the date of the initiation of services, the duration of services, and a time interval for the next periodic review, usually 6 months. The mechanism for transition to the next program, if necessary, was required in five of the Plans. Some of the policies required the inclusion of the frequency and intensity of the service delivery, and four specifically required the name of the case manager on the form.

The major concerns and many of the discussions about this legislation have to do with the interface between the family's rights and needs and the interaction of the family with the professional community or service delivery system. Few of the current policies now specify their approaches to dealing with these issues, many of which have only recently become apparent as discussions about this program occur.

Two states' policies mentioned policies about the family's rights to privacy, three referred to the concept of consent, while two referred to the need for procedures to insure confidentiality.

While three of the policies mentioned the need to identify sources of payment, none of the policies contained any references to resolution about disputes for payment of services by any party, or

for resolution of individual or systemic complaints. Of course, these policies may be contained in other legislation, regulation, or state guidelines. Six of the seven policy documents did address the need for coordination of services. Some of the policies specified that the family always has the choice of level of involvement up to and including no participation in the program.

COMMENTS

It appears that states have generally been slow in implementing this part of the legislation (P.L. 99-457, Part H) which deals with families. Only eight states currently are reporting a working policy in place. This may be due to the initial attention that the states have paid to other issues (e.g. establishing a definition for developmentally delayed, naming and activating an Interagency Coordinating Council, etc.) but it may also reflect the sensitive nature of policy that involves families.

The states have probably been well advised to move cautiously in this policy arena since there are so many delicate issues to be settled (e.g. privacy, due process, confidentiality, etc.). However, a large number of states have initiated the process by which such policies will be set. It also seems apparent that states are allowing many voices to speak on these issues prior to policy establishment- another prudent step.

It will be interesting to return a year from now, as is proposed by the Carolina Policy Studies Program, and observe the products that the states have generated in the area of family policy at that time.

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APPENDIX A

FAMILY FOCUSED ANALYSIS OF IFSP POLICIES

9/16/88

STATE_____ PERSON COMPLETING FORM_____

I. *POLICIES REGARDING THE IFSP PROCESS:*

1. Do the policies require that the IFSP be in WRITING?

YES NO

2. Is a system of CASE MANAGEMENT indicated?

YES NO

3. Does the policy specify how a CASE MANAGER will be SELECTED?

YES NO

If so, how is it defined?

4. Does the policy include provisions for CHANGING CASE MANAGERS?

YES NO

If so, how is it defined?

5. a. Is a MULTIDISCIPLINARY team ASSESSMENT indicated?

YES NO

b. Is parent/guardian input indicated as part of the assessment process?

YES NO

6. a. Is an IFSP planning/development process indicated?

YES NO

b. Is parent/guardian input indicated in the IFSP process?

YES NO

c. Is normalization or LRE mentioned?

YES NO

7. Do the policies address the unique CULTURAL needs and strengths of families?

YES NO

8. Are there TIMELINES for ...

completion of the evaluation: YES NO If yes_____

development of the IFSP: YES NO If yes_____

initiation of services YES NO If yes_____

OTHER:_____

II. *IDENTIFICATION OF FAMILY NEEDS AND RESOURCES:*

9. "What is a FAMILY?" Is this delineated and DEFINED in the policy?

YES NO

If yes, how is it defined?

10. Does the policy specify how family STRENGTHS will be identified?

YES NO

If yes, how will these be identified?

___ by family report

___ by use of standardized instrument(s)

___ clinical impressions/ structured interview

11. Does the policy specify how family NEEDS will be identified?

YES NO

If yes, how will these be identified?

___ by family report

___ by use of standardized instrument(s)

___ clinical impressions/ structured interview

___ other:

12. Does the policy specify WHO WILL IDENTIFY family strengths and needs?

YES NO

If yes, who:

OTHER INFORMATION:

III. *ARE THERE POLICIES REQUIRING THAT THE IFSP CONTAIN:*

13. a statement of the infant's or toddler's PRESENT LEVEL OF DEVELOPMENT?

YES NO

14. a statement of the FAMILY'S STRENGTHS AND NEEDS relating to enhancing the development of the family's handicapped infant or toddler?

YES NO

15. a statement of the major OUTCOMES expected to be achieved for the infant and toddler and family?

YES NO

16. a statement of the specific early intervention SERVICES necessary to meet the unique needs of the infant, toddler, and the family?

    services: YES NO

    frequency: YES NO

    intensity: YES NO

    method of delivering services: YES NO

    If specified, what are the family-specific services?

17. the projected dates for INITIATION of services?

YES NO

18. the anticipated DURATION of such services?

YES NO

19. the name of the CASE MANAGER?

YES NO

20. the steps to be taken supporting TRANSITION to services provided under part B?

YES NO

21. time periods for PERIODIC REVIEW?

YES NO

OTHER COMMENTS ABOUT OR INFORMATION CONTAINED IN THE FORM ...

IV. *FAMILY RIGHTS AND PROTECTIONS*

22. Does the policy discuss provisions for protecting a family's rights to PRIVACY?

YES NO

If yes, what provisions are identified:

23. Does the policy require and define "CONSENT"?

YES NO

If yes, specify:

24. Does the policy address CONFIDENTIALITY of records?

YES NO

If yes, specify:

25. Does the policy address COORDINATION among agencies?

YES NO

If yes, specify:

26. Does the policy address PAYMENT for what services and how this will be determined?

YES NO

27. Is there a policy for resolving DISPUTES about FINANCIAL RESPONSIBILITY (between family and agency(ies) and between agencies)?

YES NO

28. Does the policy identify procedures for resolving INDIVIDUAL CONFLICTS?

YES NO

If yes, specify:

29. Does the policy identify procedures for resolving SYSTEMIC CONFLICTS?

YES NO

If yes, specify:

30. Do the policies state whether parents have a choice about their families' level of involvement in the program?

OTHER INFORMATION: